



# Hospital Safety Guide

Helena Fox  
Parkinson's Foundation Ambassador

**Better Lives. Together.**

# My PD Story



- My sister Barb was diagnosed at 50
- Recently she was in the ER for a side effect from a motion sickness contraindicated med that was prescribed for her.
- While in the ER- They refused to give her meds from her pill pack- until I arrived and advocated for her.

**I understand the importance of preparing for a hospital visit.**

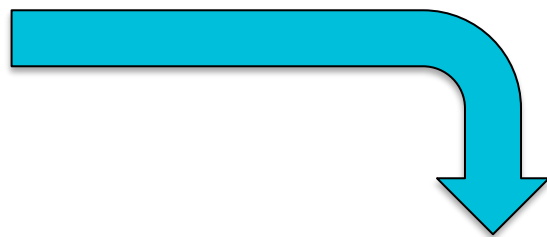
# Understanding the Risks

In this year alone, 4 of every 12 people with Parkinson's will visit the hospital.



# Understanding the Risks

In this year alone, 4 of every 12 people with Parkinson's will visit the hospital



3 of the 4 won't get the right medicine on time.

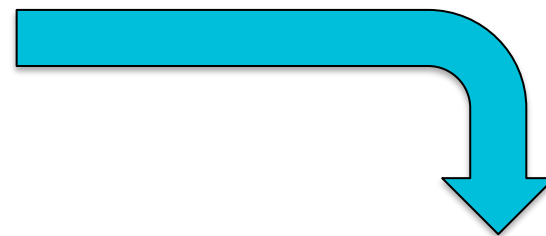


# Understanding the Risks

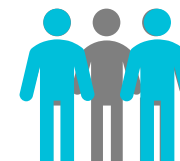
In this year alone, 4 of every 12 people with Parkinson's will visit the hospital



3 of the 4 won't get the right medicine on time.



2 of the 3 will have complications as a result.



# Medication Changes

## Missed:

- Medications are **missed entirely** by error, often because PD is not mentioned or listed in the electronic medical record (EMR) if the presenting issue is not explicitly and directly related to PD.

## Omitted:

- Medication is **withheld intentionally** when a clinician **incorrectly** assumes that
  - NPO indicates that PD medications should also be omitted
  - Severe difficulty swallowing (dysphagia) justifies the omission of medication.

## Delayed:

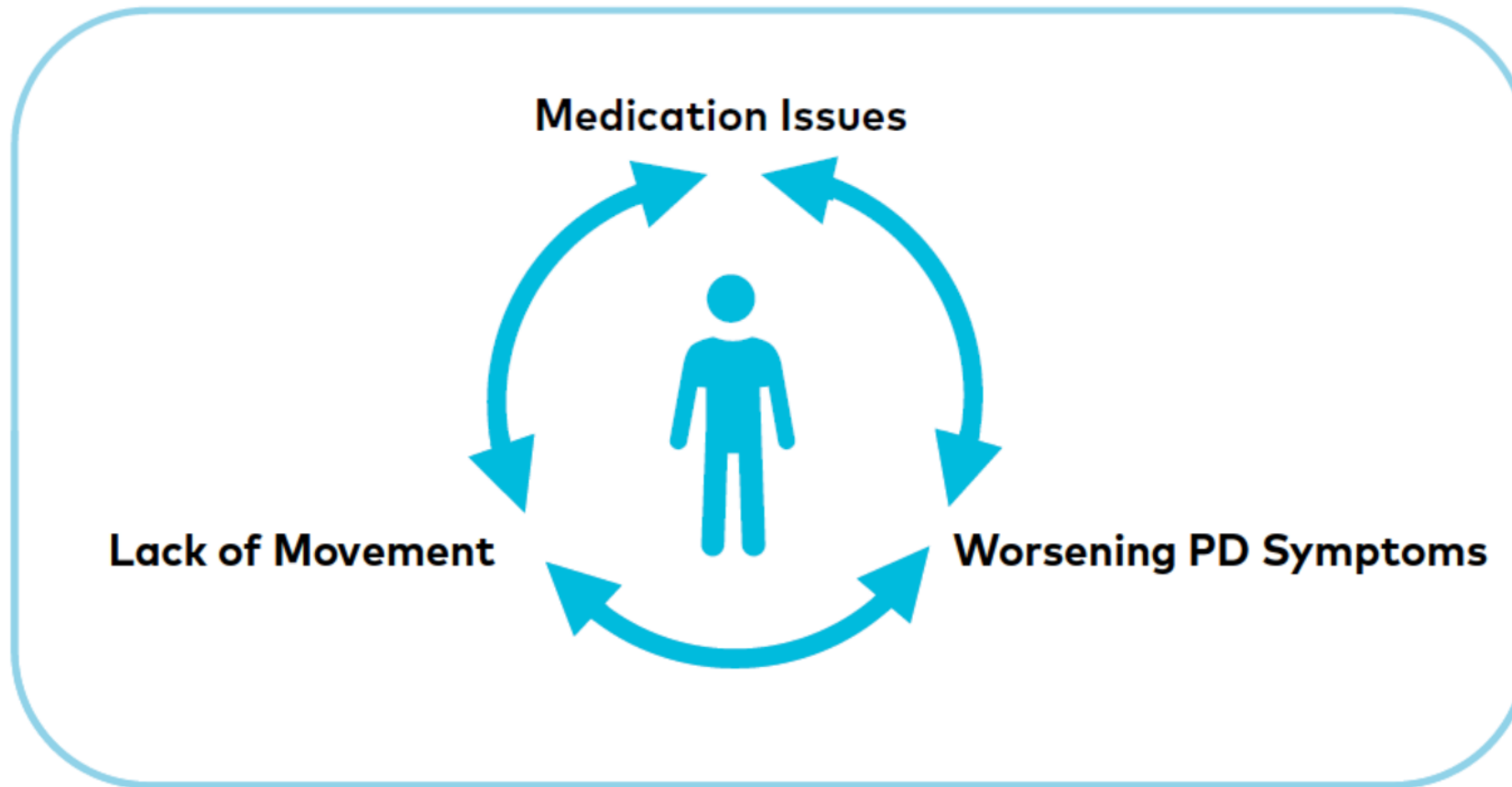
- Medications are **not distributed precisely at the home schedule**, but rather follow the standard one-hour window and/or were set to the hospital standard distribution schedule.

## Substituted:

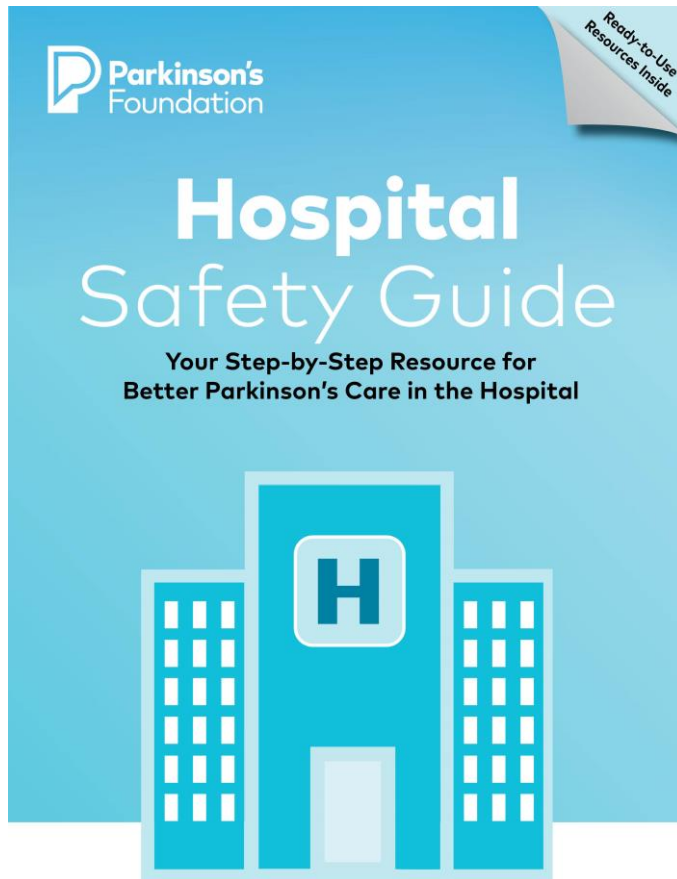
- Distribution of medication **other than the exact medication** taken by the patient because it is not available on formulary. Improper substitutions include exchanging:
  - Immediate release and continuous
  - Generic and name brand.

# Avoiding the Symptom Spiral

## The Symptom Spiral



# The Hospital Safety Guide



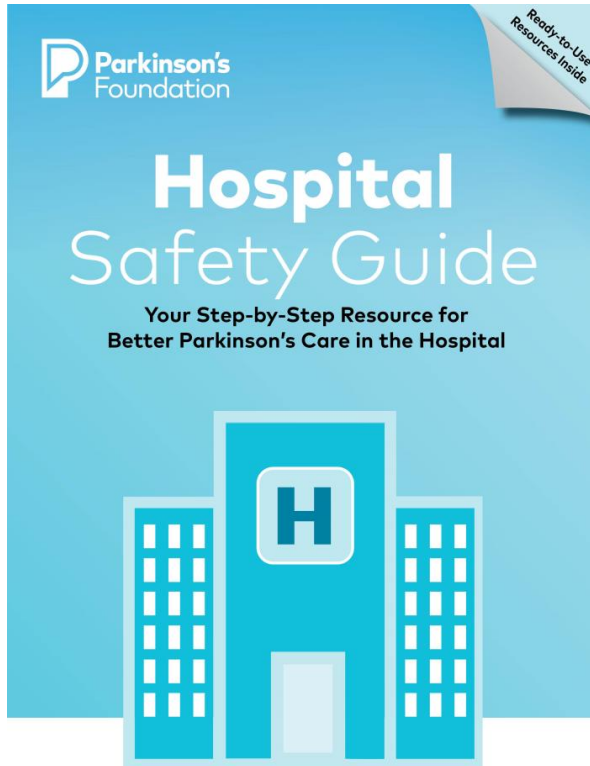
- Free Resource for the Parkinson's community
- Use to prepare **before you need it**
- Bring to the hospital as a tool during a **medical emergency**
- Bring to the hospital as a tool during a **planned medical procedure**

[Parkinson.org/HospitalSafety](https://parkinson.org/HospitalSafety)

# Planning Ahead

## Your Step-by-Step Hospital Planner

A hospital stay — whether planned or unplanned — can be especially challenging for people living with Parkinson's disease (PD). Hospital staff may not be experienced with PD. This means you and your care partner will likely need to play an active role in advocating for your Parkinson's needs. Use this planner to be prepared ahead of time.



### Preparing for a Hospital Stay

Check off each item as you complete it.



#### Carry Parkinson's identification in case of an emergency.

Use the [Medical Alert Card](#) at the back of this book or purchase a medical alert bracelet. You can also use the Medical ID feature on your smartphone.



#### Prepare a hospital "go bag."

Gather these items:

- Your [Parkinson's Foundation Hospital Safety Guide](#)
- Completed [Medication Form](#), signed [Doctor's Letter](#) (page 24)
- Current medications in labeled pharmacy bottles (2+day supply)
- Completed [Advance Directives](#) (page 8)
- Your DBS remote, if applicable

#### Keep your "go bag" by the door.

Take it with you when you go and let family and friends know where to find it in case you need to go to the hospital unexpectedly.



#### Choose a hospital care partner to accompany you in the hospital.

Learn more about how to pick a hospital care partner and how to prepare that person to advocate for you in the hospital on page 8.



#### Grab your "go bag" with completed forms and medication bottles

Ask someone reliable to bring any forgotten items to the hospital.



For more information, visit [Parkinson.org](#)  
or call our Helpline at: 1-800-4PD-INFO (473-4636).

### Once You Arrive at the Hospital

Check off each item as you complete it.



**Speak up.** Each unit will focus on what brought you there. Plan to communicate the urgency of your Parkinson's needs.

- Share the [Parkinson's Care Summary](#) (page 31)
- Remind staff you have PD before each procedure or surgery and if new medications are prescribed.
- Let your care team know if you have a DBS or Duopa device.

**Contact your PD doctor.** Let your doctor know why you are in the hospital and ask about the best way to reach out for extra support if needed.



**Stick to your regular medication schedule.** Delayed medications can lead to severe complications.

- Share your [Medication Form](#) (page 28) and explain the importance of receiving your medications within 15 minutes of your usual schedule.
- Ask to use your own supply if the pharmacy doesn't carry your medication, or you are waiting too long for your next dose.

**Ask for referrals to other specialties,** such as physical, occupational, speech/swallowing therapies, neurology or nutritional services. Each has a different role supporting your needs.



**Review the Real-Time Steps** for getting your five Parkinson's needs met throughout your hospital stay (pages 10-19).



### Preparing to Leave the Hospital

**Make sure you understand and agree with the discharge plan.** Ask questions if anything is not clear.

- If you are going **home without home care**, talk to the hospital social worker about supportive resources.
- If your discharge plan includes one of the following, use your Hospital Safety Guide to continue advocating for your PD needs.
  - **Home with home care** — care professionals come to your house to provide recovery assistance.
  - **Short-term inpatient rehabilitation** — you will receive care at a rehabilitation facility or hospital until it is safe to go home.
  - **Long-term care** — you will go to a care community, such as an assisted living or skilled nursing facility for the care you need.

# Preparing for a Hospital Stay

- ✓ **Step 1: Carry Parkinson's identification in case of an emergency**

# MEDICAL ALERT

I have **PARKINSON'S DISEASE** which could make me move slowly and have difficulty standing or speaking.

**I AM NOT INTOXICATED.**

Please call my family or physician for help.



1-800-4PD-INFO (473-4636)  
www.parkinson.org

MY NAME

HOME ADDRESS

EMERGENCY CONTACT

PHONE

PHYSICIAN

PHONE

ALLERGIES/OTHER MEDICAL CONDITIONS

## Important Information to Communicate in an Emergency

- I have Parkinson's disease.
- I need my medications on time, every time. Otherwise, my Parkinson's symptoms may become severe and uncontrollable.
- Any Parkinson's medication changes need to be discussed with my doctor.
- Many common medications for pain, nausea, depression, sleep and psychosis are not safe for people. If an antipsychotic is necessary, use pimavanserin (Nuplazid), quetiapine (Seroquel) or clozapine (Clozaril).

Please turn over this card for a list of contraindicated medications.

## Safe & Contraindicated Medications in Parkinson's Disease

### Safe Medications

### Medications to Avoid

#### Antipsychotics

- Pimavanserin (Nuplazid)
  - Quetiapine (Seroquel)
  - Clozapine (Clozaril)
- Haloperidol (Haldol) and other typical antipsychotics.  
Atypical antipsychotics other than those identified in the safe column.

#### Anesthesia & Pain Medication

Consult with the patient's PD doctor or hospital neurologist, anesthesiologist and surgeon to determine the best treatment plan whenever possible.

Local or regional anesthesia generally have fewer side effects than general anesthesia for people with PD and should be used as an alternative when appropriate.

Beware of mixing MAO-B inhibitors with the following pain medications:

- Meperidine (Demerol)
- Tramadol (Rybix, Ryzolt, Ultram)
- Droperidol (Inapsine)
- Methadone (Dolophine, Methadose)
- Propoxyphene (Darvon, PP-Cap)
- Cyclobenzaprine (Amrix, Fexmid, Flexeril)

#### Gastrointestinal (GI) & Nausea Medications

- Domperidone (Motilium)
- Ondansetron (Zofran)
- Dolasetron (Anzemet)
- Granisetron (Kytril)
- Aprepitant (Emend)
- Prochlorperazine (Compazine)
- Metoclopramide (Reglan)
- Promethazine (Phenergan)
- Droperidol (Inapsine)
- Olanzapine (Zyprexa)

**Caution:** Benzodiazepines, muscle relaxants, bladder control medications and other medications used for sleep and pain may lead to confusion, hallucinations, falls and other symptoms. Also, though most antidepressants are safe to use, amoxapine (Asendin) may lead to worsening movement symptoms for people with PD.

If a patient has a deep brain stimulation (DBS) device there are requirements for MRI scans, EKGs and EEGs.

Contact the device manufacturer or the patient's Parkinson's doctor for more information:

- Abbott: 1-800-727-7846
- Boston Scientific: 1-833-327-4636
- Medtronic: 800-510-6735

If a patient has an existing Duopa device, clinicians should:

- Turn the device off, disconnect it and remove it from the room during imaging.

Go to Duopa.com or call 1-844-386-4968 to speak with registered nurses about the pump, tubing or medication cassettes.

# Preparing for a Hospital Stay

Step 1: Carry Parkinson's identification in case of an emergency

- ✓ **Step 2: Prepare a hospital “go bag,” containing:**
  - Your **Parkinson's Foundation Hospital Safety Guide**
  - Completed **Medication Form**, signed **Doctor's Letter**
  - Current medications labeled in pharmacy bottles
  - Completed Advance Directives
  - Your DBS remote, if applicable

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

### Doctor's Letter: Parkinson's Hospital Care Needs

*Ask your Parkinson's doctor to sign this letter and to print and attach a current record of your medication schedule with specific formulations and timing.*

\_\_\_\_\_ lives with Parkinson's disease (PD). Their symptoms are managed through an individualized medication regimen. Please see the attached medication schedule for specifics.

Below I've outlined five care priorities for this patient:

**1. The patient needs their medication ordered in an individualized fashion, according to how they take them at home.**

Dosing times and medication formulations are specific to each individual patient because of the complexity of the disease. Adherence to this regimen without substitutions is imperative to avoid unnecessary pain or other severe complications.

**2. The patient needs to take their PD medications within 15 minutes of their at-home schedule.**

If this is not possible, please give the patient and/or their care partner authorization to self-administer medications while in the hospital.

If surgery is necessary, please allow patient to take their PD medications as close to the time of surgery as possible, with a sip of water or crushed in applesauce, unless it is unsafe. They should resume their PD medication as soon after surgery as is safe.

**3. The patient needs to avoid medications that make their Parkinson's worse, including dopamine-blocking medications, sedatives and certain medications for pain.**

People with Parkinson's are more prone to pneumonias and infections, which can cause sudden changes in behavior and motor function, increasing their risk of serious complications.

Should delirium occur, avoid haloperidol (Haldol) and most neuroleptics. Instead, use pimavanserin (Nuplazid), Seroquel (quetiapine) and Clozaril (clozapine).

Prochlorperazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan) and droperidol (Inapsine) are contraindicated for use in Parkinson disease.

Should an antiemetic be required, Zofran (ondansetron) is a safe alternative. For additional contraindicated medications, refer to the Parkinson's Care Summary for Health Professionals.

**4. The patient needs to move their body as safely and regularly as possible, ideally three times a day.**

Bed rest should be used as a last resort. Consult with physical and occupational therapy to determine what is safe.

**5. The patient needs to be screened for swallowing changes and the risk of aspiration pneumonia needs to be minimized.**

Avoid withholding medications whenever possible. Consult with speech-language pathology as needed.

**The below strategies can also help reduce complications:**

- People with PD are prone to constipation. A good bowel regimen can improve medication absorption.
- Should they require an NG tube, carbidopa/levodopa 25/100 immediate-release tablets can be crushed and administered via the tube.

**Should you have additional questions or concerns, please don't hesitate to contact me.**

Doctor's Printed Name:

Doctor's Phone Number:

\_\_\_\_\_

\_\_\_\_\_

Doctor's Signature:

Doctor's Email:

\_\_\_\_\_

\_\_\_\_\_

This letter is part of the Parkinson's Foundation Hospital Safety Guide. For more information, go to [Parkinson.org/HospitalSafety](http://Parkinson.org/HospitalSafety).



# Medication Form

Complete this form and attach it to your signed Doctor's Letter. Give both to your hospital care team. Fill out a new form when your prescriptions change and keep an updated version in your Hospital Safety Guide.

YOUR NAME \_\_\_\_\_ DATE FORM FILLED \_\_\_\_\_

**Important names and numbers**

CARE PARTNER \_\_\_\_\_ RELATIONSHIP \_\_\_\_\_ PHONE \_\_\_\_\_

PARKINSON'S DOCTOR \_\_\_\_\_ PHONE \_\_\_\_\_

PRIMARY CARE DOCTOR \_\_\_\_\_ PHONE \_\_\_\_\_

PHARMACY \_\_\_\_\_ PHONE \_\_\_\_\_

I was diagnosed with Parkinson's disease in \_\_\_\_\_ (year).

**Special Considerations**

- I have a deep brain stimulation device.
- I have a Duopa pump.
- I have dementia.
- I get dizzy or feel faint.
- I have special dietary needs.
- I have balance issues.
- I have trouble swallowing.
- I experience hallucinations or delusions as part of my Parkinson's.
- I sometimes feel disoriented or confused.
- Other: \_\_\_\_\_

I also have the following conditions (list them below):

**Medication List** (continued on back)

List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements. See page 27 for an example and more information.

TIME	MEDICATION	DOSE	NOTES
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

### Sample Medication Form Entries

Time	Medication	Dose	Notes
8 am	Carbidopa/levodopa immediate-release (IR) tablets (Sinemet)	25/250 mg	
With breakfast	polyethylene glycol 3350 (MiraLax)	17 g	Mix with water or juice, drink with breakfast

# Preparing for a Hospital Stay

Step 1: Carry Parkinson's identification in case of an emergency

Step 2: Prepare a hospital "go bag," containing:

- Your **Parkinson's Foundation Hospital Safety Guide**
- Completed **Medication Form**, signed **Doctor's Letter**
- Current medications labeled in pharmacy bottles
- Completed Advance Directives
- Your DBS remote, if applicable

✓ **Step 3: Choose a hospital care partner to accompany you in the hospital**

# The Role of Care Partners in the Hospital

Think about all your options when selecting someone to support and advocate for you in the hospital:

- Your *primary* care partner
- An adult child
- A sibling
- A close friend
- A paid professional advocate

**Make sure that they**



Understand you and your needs

---

**Make sure that you**



Sign any required documents in advance to ensure they can speak on your behalf

# Communicating Your Needs

- **Preparation and clear communication** can help you minimize complications and recovery time.
- The Parkinson's Foundation – together with people impacted by Parkinson's, healthcare professionals and specialists – developed the **Five Parkinson's Care Needs** to help you and your hospital care partners **communicate your needs** during a hospital visit.



# My Five Parkinson's Care Needs



I need my hospital chart to include my exact medications and reflect my at-home schedule.



I need to take my Parkinson's medications within 15 minutes of my usual schedule.



I need to avoid medications that make my PD worse.



I need to move my body as safely and regularly as possible, ideally three times a day.



I need to be screened for swallowing changes.

# My Five Parkinson's Care Needs



**Need 1:** I need my hospital chart to include my exact medications and reflect my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my PD worse.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes.



## NEED 1:

**I need my hospital chart to include my exact medications and match my at-home schedule.**

### Why is this important?

People with Parkinson's typically take different medications at specific times throughout the day (and sometimes at night) to function at their best. As PD progresses, medication routines often become more complex. For example, a person with PD may go from taking medication twice a day to taking it every two hours to maintain consistent dopamine levels in the brain.

### REAL-TIME STEPS

- 1 Share Important Forms**  
Give important documents (page 24) to staff, including:
  - Parkinson's Care Summary
  - Doctor's Letter
  - Medication Form
- 2 Review Medications & Timing**  
Verbally review your hospital medication list and schedule with the hospital care team. You can also request a printout.
- 3 Offer Home PD Prescriptions**  
If the pharmacy does not stock one of your medications, ask if you can provide your own supply in the original bottles.

If you are having trouble getting your medications listed correctly, review pages 6-7 for next steps.

## CHALLENGES

- **Hospitals often follow standardized medication schedules** to ensure timely administration for most patients. Special care is needed to prevent these schedules from replacing your unique medication schedule.
- **If the hospital pharmacy does not carry your specific medication, the pharmacist may try to make a substitution.** A different type or dose of the same medication may not provide enough symptom relief or may increase your side effects.

### Understanding Hospital Medication Schedules

Make sure the hospital records your exact medication times rather than the number of times per day you take them. Otherwise, the hospital will follow **their** schedule instead of **yours**. See below for how much the hospital schedule could vary from your own:

**Sample Home Schedule:**  
 8 a.m.  
 noon  
 4 p.m.  
 8 p.m.

**Standard Hospital 4x/Day Schedule:**  
 6 a.m.  
 noon  
 6 p.m.  
 midnight



My husband was hospitalized for two weeks for a broken hip following a fall. It was extremely difficult to get his same PD meds and doses since prescriptions from home were not permitted. Once we got the correct prescriptions, receiving them on his home schedule was also a challenge. I had to speak with each new shift nurse every day to confirm what meds were to be given and their scheduled timing. A sheet noting his meds and their schedule was provided to nursing staff, who ultimately added it to my husband's chart.

- Tamara, care partner

## REAL-TIME STEPS

1

### Share Important Forms

Give important documents (page 24) to staff, including:

- Parkinson's Care Summary
- Doctor's Letter
- Medication Form

2

### Review Medications & Timing

Verbally review your hospital medication list and schedule with the hospital care team. You can also request a printout.

3

### Offer Home PD Prescriptions

If the pharmacy does not stock one of your medications, ask if you can provide your own supply in the original bottles.



# My Five Parkinson's Care Needs



**Need 1:** I need my hospital chart to include my exact medications and reflect my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my PD worse.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes.



## NEED 2:

**I need to take my Parkinson's medications within 15 minutes of my usual schedule.**

### Why is this important?

Parkinson's symptoms return when dopamine-replacing medications "wear off" in between doses. Depending on the individual, even small changes to medication timing can worsen symptom control and slow recovery. Delayed or missed doses can lead to falls, difficulty participating in rehabilitation and being less prepared to go home after leaving the hospital.

### REAL-TIME STEPS

- 1 Explain the Impact**  
Describe your symptoms and how they are affected when you do not receive medication on time, every time.
- 2 Offer Reminders**  
Let the nurse know when it's almost time for your medication.
- 3 Follow Up**  
Reconfirm your medication schedule with your nurse and share the following documents (page 24) again if necessary:
  - Parkinson's Care Summary
  - Doctor's Letter
  - Medication Form

If you are having trouble getting your medications on time, review pages 6-7 for next steps.

## CHALLENGES

- Many hospitals allow nurses to give medications up to an hour before or after the scheduled time. Taking your PD medication more than 15 minutes before or after your scheduled time may affect your ability to move and function.
- The hospital is a busy place. Between members of your care team checking on you, rehabilitation, and diagnostic testing or surgical procedures, taking your medications on time may get a little bit trickier.

### Understanding How to Prepare for Surgery

Scan the QR code to listen to a podcast in which a movement disorders specialist explains how to prepare for a routine outpatient procedure.



**TIP:** Schedule the procedure first thing in the morning or when your medications are working best to minimize medication schedule interruptions.

Read about more ways to prepare for a surgery on pages 20-21.



While in the hospital for a hip replacement, I went for an extended period of time without my meds despite our constant reminders. We had to follow up again and again! We learned that we have to be our own advocates and the Foundation's advice on how to prepare came in very handy.

- Bubba, person with Parkinson's

## REAL-TIME STEPS

1

### Explain the Impact

Describe your symptoms and how they are affected when you do not receive medication on time, every time.

---

2

### Offer Reminders

Let the nurse know when it's almost time for your medication.

---

3

### Follow Up

Reconfirm your medication schedule with your nurse and share the following documents (page 24) again if necessary:

- Parkinson's Care Summary
- Doctor's Letter
- Medication Form



# My Five Parkinson's Care Needs



**Need 1:** I need my hospital chart to include my exact medications and reflect my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my PD worse.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes.



### NEED 3:

**I need to avoid medications that make my Parkinson's worse. These medications include those that block dopamine, sedatives and certain pain medications.**

#### Why is this important?

Lack of dopamine in the brain is the primary cause of Parkinson's movement symptoms. Dopamine-blocking medications, such as antipsychotics like haloperidol (Haldol) and olanzapine (Zyprexa, Zyprexa Zydis), and anti-nausea medications like metoclopramide (Reglan) and prochlorperazine (Compazine), can worsen these symptoms and cause harmful side effects. Other medications commonly prescribed in the hospital may cause or increase confusion and sleepiness and result in falls.

#### REAL-TIME STEPS

- 1 Identify Harmful Medications**  
View the list of harmful medications on the Parkinson's Care Summary (page 31) with your hospital care team.
- 2 Review Possible Interactions**  
Check if any of your prescribed medications are on the list of contraindicated medications (page 32). Watch out for medications prescribed before or after surgery, as well as those prescribed for confusion and behavioral changes.
- 3 Seek Appropriate Alternatives**  
If you are prescribed a medication not appropriate for a person with PD, ask for a safe alternative.

If you are having trouble getting a safe medication alternative, review pages 6-7 for next steps.

#### CHALLENGES

- Some medications used in the hospital to treat nausea, confusion and psychosis (hallucinations and delusions) can worsen Parkinson's symptoms. **Staff may be unfamiliar with safe PD medication alternatives.**

#### Understanding Confusion in the Hospital

Medication side effects, infection, lack of sleep, an unfamiliar setting or a surgery can cause confusion. Sometimes this leads to behavioral changes, such as aggression, refusal to take pills or psychosis. If an antipsychotic is necessary, pimavanserin, clozapine or quetiapine are the only options recommended for people with PD.

These symptoms often disappear once the underlying cause is treated, whether by addressing an infection or reducing or eliminating certain medications. Please note, some PD medications need to be decreased slowly.



While hospitalized, I learned I was going to receive a shot of Abilify, an antipsychotic that can make PD symptoms worse. I called the Parkinson's Foundation Helpline and the information specialist was able to fax the Parkinson's Care Summary for Health Professionals to my doctor, who read that Abilify is contraindicated and then chose a more appropriate medication.

- Anonymous Helpline Caller, person with Parkinson's

## REAL-TIME STEPS

1

### Identify Harmful Medications

View the list of harmful medications on the Parkinson's Care Summary (page 31) with your hospital care team.

2

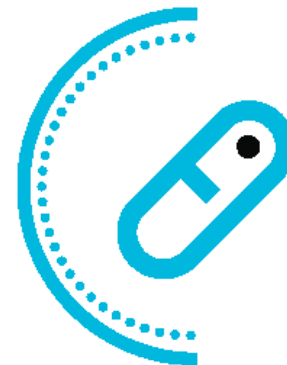
### Review Possible Interactions

Check if any of your prescribed medications are on the list of contraindicated medications (page 32). Watch out for medications prescribed before or after surgery, as well as those prescribed for confusion and behavioral changes.

3

### Seek Appropriate Alternatives

If you are prescribed a medication not appropriate for a person with PD, ask for a safe alternative.



# My Five Parkinson's Care Needs



**Need 1:** I need my hospital chart to include my exact medications and reflect my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my PD worse.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes.



#### NEED 4:

I need to move my body as safely and regularly as possible, ideally three times a day.

#### Why is this important?

Staying active in the hospital is key to maintaining abilities and recovering faster. Regular movement has many benefits, including reducing muscle loss, helping with sleep, improving focus and managing constipation.

For people with PD, regular movement — often coupled with physical and occupational therapy — is important for controlling PD symptoms, preventing falls and minimizing complications.

#### REAL-TIME STEPS

- 1 Communicate Your Needs**  
Share the Parkinson's Care Summary and the Doctor's Letter (page 24) with your hospital care team and point out that you need to move regularly to manage your PD symptoms. Describe your typical physical activity and ask for safe alternatives.
- 2 Continue Safe Movement**  
If safe, continue daily activities, such as dressing, walking to the bathroom, sitting in a chair for meals and taking short walks. If you can't get up, you may be able to exercise in bed or in a chair.
- 3 Request Expert Help**  
Ask for rehabilitation therapy (physical and occupational therapy) if you need help moving safely.

If you are having trouble getting a referral to physical or occupational therapy, review pages 6-7 for next steps.

#### CHALLENGES

- **Nursing staff may not be aware of the important role Parkinson's medications have in helping people with PD move.** They may also not know that lack of movement can worsen tremor, stiffness, balance and walking problems.
- **Your care team may limit your movement to keep you safe,** especially if you are weak after surgery, have low blood pressure or have other issues that put you at risk of falling. You also may require assistance to get out of bed, but sometimes nurses get busy, and hospital staff may not feel it is safe for family to help.

#### Understanding Your Exercise Options

Your health condition could make it challenging to keep moving. If standing or walking are not safe, ask your care team if you can do seated or bed exercises. Here are some options they may recommend:

**Arm Alphabet:** With your arm straight out in front of you, write the alphabet or your name in the air as big as you can. Repeat with the other arm.

**Ankle Circles:** Kick your foot out in front of you and move your foot in slow circles. Repeat with the other foot.

**Head Turns:** Slowly rotate your head from left to right 5x making sure you feel a slight stretch on each side. Repeat right to left. Next, nod your head up and down 5x.



My wife was in the hospital due to a constipation issue, a common symptom of Parkinson's. Once she was settled into her room she was asked if she was able to get up and walk on her own. She responded "Yes, with the help of a walker." A physical therapist came in to check her out and provided the walker. She was able get out of bed and walk on her own.

- Geri, care partner

## REAL-TIME STEPS

1

### **Communicate Your Needs**

Share the Parkinson's Care Summary and the Doctor's Letter (page 24) with your hospital care team and point out that you need to move regularly to manage your PD symptoms. Describe your typical physical activity and ask for safe alternatives.

2

### **Continue Safe Movement**

If safe, continue daily activities, such as dressing, walking to the bathroom, sitting in a chair for meals and taking short walks. If you can't get up, you may be able to exercise in bed or in a chair.

3

### **Request Expert Help**

Ask for rehabilitation therapy (physical and occupational therapy) if you need help moving safely.



# My Five Parkinson's Care Needs



**Need 1:** I need my hospital chart to include my exact medications and reflect my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my PD worse.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes.



## NEED 5:

**I need to be screened for swallowing changes to safely maintain my medication routine and minimize my risk of aspiration pneumonia and weight loss.**

### Why is this important?

Difficulty swallowing, called dysphagia, is common for people with Parkinson's. It can cause problems eating, drinking or taking pills. Dysphagia can lead to choking or aspiration pneumonia — an infection caused by food or liquid entering the lungs. Aspiration pneumonia is a common cause of death for people with PD.

A bedside swallow screening and consultation with a speech-language pathologist can identify issues early and provide safety measures to decrease risks.

### REAL-TIME STEPS

- 1 Share Swallowing Issues**  
Tell staff if you have had problems swallowing in the past and ask for a speech-language pathology consultation.
- 2 Avoid Medication Pauses**  
Discuss safe ways to continue taking your medications with your nurse, such as with a sip of water or crushed with applesauce (page 22).
- 3 Minimize Risks**  
To decrease risk of aspiration pneumonia, eat when PD meds are working and you have energy. Sit up for meals. Take smaller bites. Brush your teeth, tongue and mouth before and after eating to reduce bacteria.

If you are having trouble getting a speech-language therapy consultation or finding safe ways to continue to take your medications, review pages 6-7 for next steps.

## CHALLENGES

- People with PD may have undetected or minor swallowing issues that could worsen and create severe complications during a hospital stay. A swallowing screening and a speech-language pathologist evaluation can help identify dysphagia but may not be routinely ordered.
- To decrease choking or aspirating, staff may order "NPO" (nothing by mouth), meaning food, liquids and medications cannot be swallowed. If the medication is not given in another way, it may be stopped completely. Staff may not realize this could worsen your PD symptoms and swallowing issues, and lead to unintentional weight loss. Read more on page 23.

### Understanding Aspiration vs. Aspiration Pneumonia

**Aspiration** is when something you swallow goes down the wrong way and enters your airways or lungs. **Aspiration pneumonia** is when bacteria from your mouth gets pulled down into the lungs and causes an infection.

Reducing the risk of aspiration pneumonia is a two-part process that involves not only preventing swallowing issues, but also reducing bacteria in your mouth by cleaning teeth and mouth regularly.



My friend had a medical emergency and had to go to the hospital. He usually takes Parcopa, but it wasn't available in the hospital pharmacy. I called the Parkinson's Foundation Helpline looking for another way he could get his meds. I was just wondering what other people do in this situation. The Helpline specialist suggested asking the nurse about crushing his medication and putting it in applesauce. I let his wife know about this option.

- Cathy, friend of a person with Parkinson's

## REAL-TIME STEPS

1

### Share Swallowing Issues

Tell staff if you have had problems swallowing in the past and ask for a speech-language pathology consultation.

2

### Avoid Medication Pauses

Discuss safe ways to continue taking your medications with your nurse, such as with a sip of water or crushed with applesauce (page 22).

3

### Minimize Risks

To decrease risk of aspiration pneumonia, eat when PD meds are working and you have energy. Sit up for meals. Take smaller bites. Brush your teeth, tongue and mouth before and after eating to reduce bacteria.



# How to Order Your Guide

**Step 1: Visit**  
[Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety)



**Step 2: Scroll down until you see “Order your free Hospital Safety Guide”**

## Order your free Hospital Safety Guide

At the Parkinson's Foundation, it is our mission to help people with Parkinson's disease live better lives, and that includes staying safe while in the hospital. Our Hospital Safety Guide is available to everyone in the Parkinson's community at no cost to order or download.

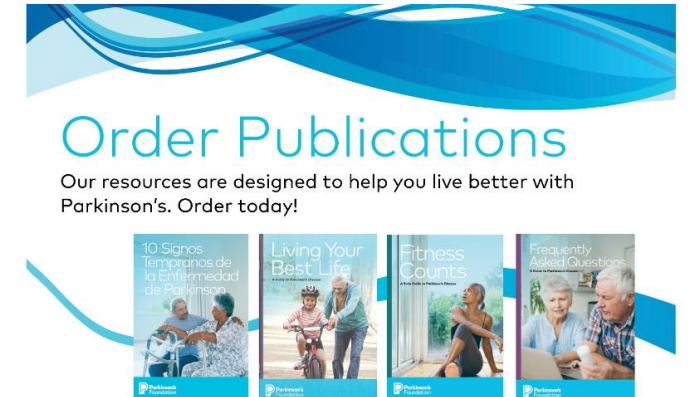


**ORDER NOW >**

**DOWNLOAD NOW >**

We currently only ship the guide within the U.S. If you are outside the U.S., we recommend downloading the guide and printing the essential resources outlined below.

**Step 3: Click “Order Now” and complete the Publications Order Form**



## How to Order

1. **Select your publications** from the list below by clicking on the box to the left of each description.
2. **Fill in your shipping information.**
3. **Click Submit.**

# Prepare Today!

- ✓ Order and/or download the free Hospital Safety Guide. Visit [Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety) to learn more.
- ✓ Review the **5 Parkinson's Care Needs**
- ✓ Complete the **Step-by-Step Hospital Planner**
- ✓ Prepare your hospital “go bag”
- ✓ Do not wait for an emergency — talk with family and friends to choose the best person to fill the role of Hospital Care Partner

**Questions?** Contact the Parkinson's Foundation Helpline:



1-800-4PD-INFO (1-800-473-4636)



Helpline@Parkinson.org